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Citation for published version (APA):

Stevens, E., Emmett, E., Wang, Y., McKeivitt, C., & Wolfe, C. (2017). *The Burden of Stroke in Europe: The challenge for policy makers*. Stroke Alliance for Europe.
https://www.stroke.org.uk/sites/default/files/the_burden_of_stroke_in_europe_-_challenges_for_policy_makers.pdf

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S·A·F·E

Stroke Alliance For Europe

THE STROKE PATIENT
VOICE IN EUROPE



THE BURDEN OF **STROKE** IN EUROPE

the Challenge for Policy Makers

King's College London

for the

Stroke Alliance for Europe (SAFE)

Stroke Alliance for Europe

Stroke Association House

240 City Road, London

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SAFE is registered in Belgium

as a non-profit making organisation

(Association sans but lucratif).

ASBL 0661.651.450



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THE BURDEN OF STROKE IN EUROPE

the Challenge for Policy Makers

King's College London
for the
Stroke Alliance for Europe (SAFE)



CONTENTS

Authors.....	1
Acknowledgements.....	1
Foreword	2
Recommendations	4
SAFE's call to action to EU policy makers	5
What needs to change.....	6
Stroke In Europe.....	8
What is stroke?	9
The size of the problem.....	9
Future projections.....	11
The economic burden of stroke	13
European stroke data – registers and audits	15
Stroke Prevention And Care Across Europe.....	16
Preventing stroke	17
Emergency response to stroke	20
Stroke Unit care.....	23
Thrombolysis.....	26
Rehabilitation in hospital and in the community	28
Long term support for stroke survivors and families	30

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ACKNOWLEDGEMENTS

The authors acknowledge support from the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) South London at King's College Hospital NHS Foundation Trust, and the NIHR Biomedical Research Centre, Guy's and St Thomas' NHS Foundation Trust and King's College London, UK.

The study team would like to acknowledge the support of the study steering group and contributing editors of the report, drawn from the board of SAFE and from the Stroke Association in the UK. We would like to thank the clinicians, researchers and stroke support organisation representatives across Europe who took the time to respond to our questions. We would also like to thank Professor Anthony Rudd, National Clinical Director for Stroke with NHS England, for his comments on a draft of the Recommendations.

This research and report have been sponsored by *Amgen, Bayer, Boehringer Ingelheim, Daiichi-Sankyo, Ipsen, Merz and the Bristol-Myers Squibb and Pfizer Alliance* through an educational non restricted grant. Without their generosity we would not have been able to produce such an important and timely piece of research. They had no influence on the research priorities or editorial content of this report.

Foreword

Across the European Union over the last two decades there has been a welcome reduction in the proportion of people having a stroke (when taking age into account). And people's chance of recovering from their stroke has greatly improved. Europe boasts some of the best stroke care in the world, has pioneered important developments in the prevention and treatment of stroke, has an active stroke research community and has patient advocacy organisations in almost every country.

But, despite this progress, the numbers of strokes are set to rise because the proportion of Europeans over 70 is increasing. The projections in this report indicate that between 2015 and 2035, overall there will be a 34% increase in total number of stroke events in the European Union from 613,148 in 2015 to 819,771 in 2035. Stroke prevention should, therefore, be a high priority. Despite most EU member states having guidelines for risk factors such as high blood pressure and atrial fibrillation, there is significant under-treatment. And well below half of all people treated for high blood pressure, for example, are actually on enough medication to get their blood pressure below the desired target level.

While death rates from stroke have been falling over the last twenty years, your chance of dying from a stroke varies greatly according to where in Europe you live. Currently, rates of deaths from stroke in different EU member states range from 30 per 100,000 of the population to 170 per 100,000 of the population. Falling death rates due to better and quicker treatment mean that there will be more people surviving their strokes and living with the consequences. So the estimated total cost of stroke in the EU (healthcare and non-healthcare costs) of an estimated 45 billion euros in 2015 is set to rise.

When it comes to stroke care, the inequalities across the continent are apparent. For example, in some EU member states we are concerned about how effective public education campaigns to encourage an emergency response to stroke are. But in many places across Europe emergency services specialised in stroke simply do not exist. Thrombolysis (clot-busting treatment) rates vary from less than 1% of patients to 16%.



Despite over thirty years of evidence showing the difference stroke units make, only about 30% of patients receive stroke unit care across the EU. The proportion of people who get treated on a stroke unit varies from less than 10% to over 80%, depending on where you live. Existing European Stroke Organisation guidelines are not consistently applied and a continent-wide, evidence-based system of specialist stroke care is yet to be realised.

Access to rehabilitation and long-term support is also a significant issue in many EU member states. Provision of rehabilitation is not widely monitored in many parts of Europe and even where there are audits, people often receive therapies during only brief periods of each day in hospital. In several countries there is very limited access to therapies once people are at home. There are no outpatient therapy services in two out of every five EU member states.

SAFE commissioned the Burden of Stroke study to show each EU member state where it stands in terms of the stroke burden and how well it is meeting the need for acute and follow-up care, including examples of good practice. The research findings for this report have led SAFE to generate a number of action points for EU policy makers, national health service representatives and stroke support organisations. References have not been included in this report for ease of reading. All references are in a longer report that can be found at www.strokeeurope.eu.

SAFE is a non-profit-making organisation that represents a range of stroke patient groups from across Europe whose mutual goal is to drive stroke prevention and care up the European and national political agendas, prevent the incidence of stroke through education and support stroke care and patient centred research. SAFE aims to raise awareness of the major impact stroke has on individuals and on the health and economy of Europe.

Jon Barrick, SAFE President

RECOMMENDATIONS



SAFE's call to action to EU policy makers

The inequalities in stroke risk and stroke provision across Europe revealed in this report should be of great concern to European policy makers, especially as we predict a 34% rise in the number of people having strokes by 2035. SAFE wants a Europe where everyone has the opportunity to prevent a stroke, and those who do have a stroke get treated as quickly as possible in a stroke unit; get the assessment and rehabilitation they need to maximise their recovery; and get the long term support they need to regain as much independence as possible. We are concerned that the lack of unified data on stroke events and outcomes in Europe is a barrier to comparing stroke care both within

and between different healthcare systems and, therefore, to improving stroke care.

SAFE believes that each EU member state should have a national stroke strategy actively supported and sponsored by Government that covers the whole stroke pathway to include awareness, prevention, diagnosis, treatment, transfer of care, specialist rehabilitation and reassessment, long-term care and support, social integration and participation in community life and end-of-life care. Representatives from the wide range of professionals who support people with stroke, people who have had a stroke, carers and voluntary associations should all be involved in creating such strategies.

Therefore, SAFE calls on EU policy-makers (Commission, Parliament, Council) to:

Facilitate coordinated, Europe-wide data collection. In particular, the European Commission and the Joint Research Centre should support and promote the use of a robust Europe-wide stroke register to assess stroke prevention initiatives and the quality of care along the whole stroke pathway.

Incorporate the stroke indicators used in this report (e.g. blood pressure management, door-to-needle time, coordinated discharge and post-discharge rehabilitation assessment) in the EU's work on the evaluation of the performance of health systems, as they are good measures to assess the efficiency of care organisation and delivery in member states.

Support, together with member states, a Joint Action on stroke, in the framework of the EU Health Programme. The Joint Action should focus on addressing the following topics: 1) data collection, 2) prevention, 3) promotion and implementation of national stroke strategies, and 4) performance assessment. Stroke support organisations (SSOs) should be actively involved in the Joint Action, and their crucial role throughout the stroke pathway, and in policy formation, should be enshrined in the national stroke strategies.

Support research into patient-reported experience, outcome measures and quality of life across Europe. This is linked to the need for more research on long-term management and support so that best practice and the effectiveness and cost-effectiveness of different models can be identified. SAFE believes strongly that patients and patient organisations/SSOs should be actively involved in these studies as participants and co-researchers and that building the capacity for their participation is also vital.

What needs to change

The evidence in this report highlights improvements that are needed across the whole stroke care pathway. The wide disparities in provision between countries and the inequalities within countries found in this report should be of concern to all European policy makers as well as to national Governments and health planners.

Healthcare planning

The number of people having a stroke and the number of people living with the long-term effects of stroke will rise in the coming decades. Effective healthcare planning and adequate resource allocation across Europe is needed to deal with this, taking into account that the financial burden of stroke is to a large extent borne by stroke survivors themselves and their families.

Prevention, hypertension & atrial fibrillation

Across Europe we need rapid and concerted action to prevent stroke and, especially, improvement in the detection and treatment of high blood pressure (hypertension) and atrial fibrillation (an abnormal heart rhythm with rapid and irregular beating).

A more systematic, evidence-based approach to public education across the EU is required to improve knowledge of the modifiable risk factors for stroke, i.e. an awareness that these factors significantly increase a person's risk of having a stroke, but can be treated in most cases. Joining forces with public education efforts in relation to other cardiovascular diseases could create a more powerful message and greater impact.

Stroke as an emergency

We need to reduce delays in people getting emergency stroke care by carrying out continuous education of the public and health professionals to recognise stroke and always treat it as an emergency; and by improving emergency care pathways. There should be enough trained stroke specialists available and acute and emergency stroke services should be organised to maximise fast patient access to emergency care.

Life after stroke support

Across Europe there is very little provision for the long-term needs of stroke survivors. SAFE calls on all European countries to consider implementing frameworks for support after stroke, ensuring a holistic approach to tackling “life after stroke” issues and recognising the roles of carers and families.

Recognising the value of emotional, practical and financial support for stroke survivors and their families, SAFE believes that stroke support organisations can play an important role in the overall stroke pathway. Health authorities and Governments should provide funding and support to help build their capacity.

Acute stroke care

Stroke units save lives and improve outcomes so improving stroke unit provision is a priority. Currently only 30% of people who have a stroke get treated in a stroke unit. Everyone who has a stroke should be treated in a stroke unit that meets Europe-wide agreed organisational and quality standards.

Thrombolysis is still under-performed across all of Europe. Structural changes to acute stroke care within the respective national and local context could help to improve thrombolysis rates and patient outcomes.

Medical and technological advances leading to new treatment options, such as for restoring blood flow and improving brain function, must be made available to all patients across Europe, for example by creating hospital networks.

Rehabilitation

We need a step change in the provision of rehabilitation and long-term support for stroke survivors and their families. All stroke survivors should get an early assessment for rehabilitation in hospital, and receive appropriate levels of therapy both in hospital and following discharge. Post-hospital reviews should be available to all stroke survivors, wherever they live in Europe, and they should be able to get therapy (including for their psychological and non-physical needs) for as long as they need it.

STROKE IN EUROPE



What is stroke?

Stroke is a brain attack that affects 17 million people worldwide each year. It is the second most common cause of death and a leading cause of adult disability.

There are two main types of stroke. The most common, ischaemic stroke, accounts for around 85% of all strokes, and occurs when blood flow to the brain is blocked by a clot or narrowed blood vessels. The second type, haemorrhagic, is caused by a burst blood vessel. Strokes are of varying severities (some resolve within 24 hours and are known as transient ischaemic attacks or TIAs) and have different impacts depending on the site and extent of brain damage.

Stroke survivors can experience a wide range of long lasting outcomes including problems with mobility, vision, speech, memory, personality changes, fatigue and depression.

"I had a heart attack and a stroke at the same time. The day before [the stroke], I couldn't feel my arm for a couple of seconds. At this moment I didn't notice the warning signs of stroke, and eleven hours later while I was having a shower I suddenly felt like something had exploded in my head. I was not able to speak any more and I felt like the right side of my body had disappeared. I couldn't see with my right eye like during a migraine, and I had a sudden, terrible headache."

(Female stroke survivor, 37,
Netherlands)



The size of the problem

It is important to have reliable information about the number of people across Europe who have a stroke and what happens to them. How do different health and social care systems across Europe differ from one another in their outcomes and what can we learn from each other about what works well?

The way that information is gathered about stroke varies widely across Europe with regards to the extent and methods of data collection. This makes accurate comparisons between studies and countries difficult. To overcome this problem, the Global Burden of Disease (GBD) study, a large, global research program, has developed statistical methods to calculate best estimates for epidemiological parameters for all countries in a standardised way. However, differences in country estimates between the GBD study and national or local data, e.g. UK national stroke audit, underline the fact that most country estimates, including those of the GBD study, have a significant level of uncertainty attached.

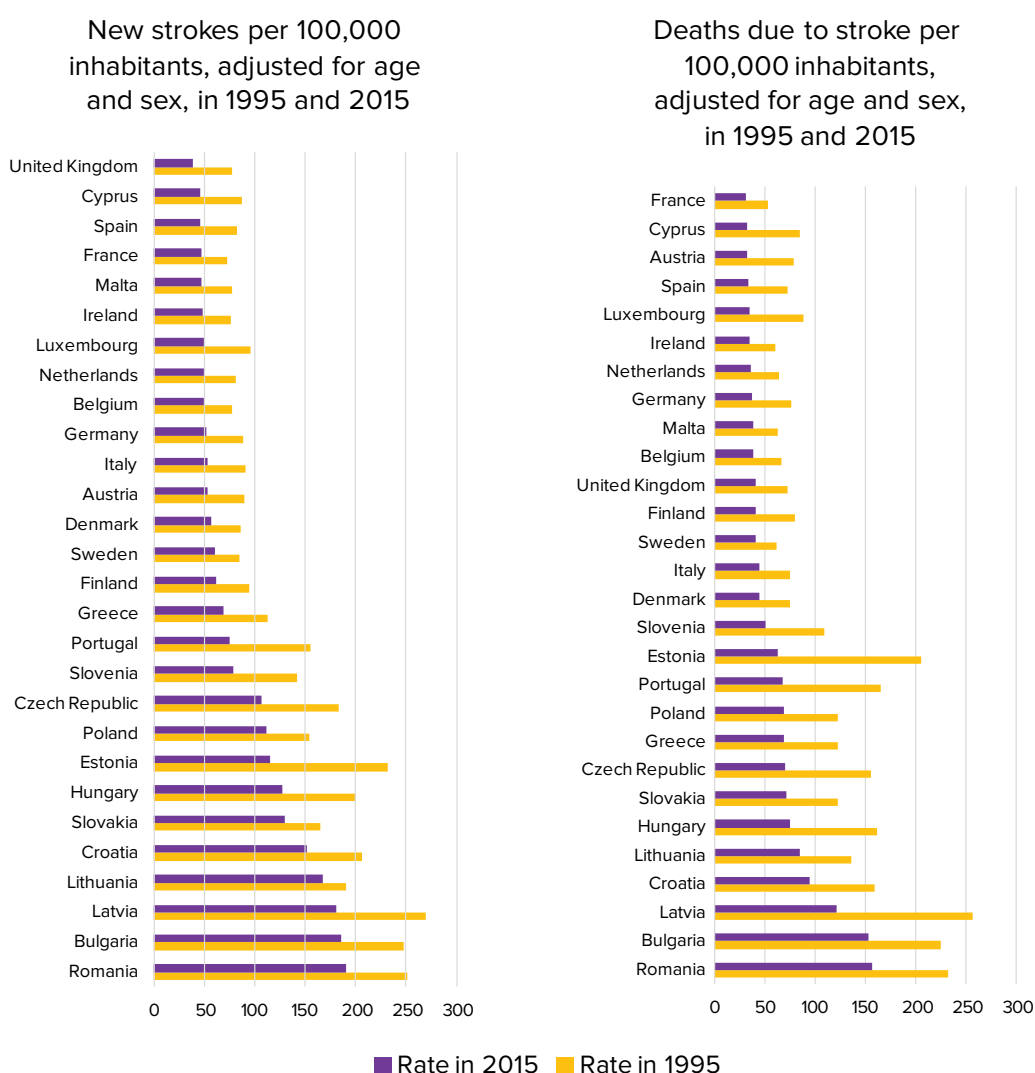
There are large variations in the burden of stroke. Generally, the estimated number of strokes and deaths due to stroke are significantly larger in Eastern European countries. Explanations for these variations include different risk factor profiles, such as high blood pressure, lifestyle factors, socio-economic factors and environmental factors, as well as different access to and quality of healthcare (e.g. risk factor control).

Encouragingly though, the rate of new strokes and stroke deaths (when adjusted for age) has decreased significantly over the last two decades in all countries.

Decreasing rates are generally attributed to successful prevention strategies, e.g. hypertension control, smoking cessation.

However, on average, relative improvements have been larger in Western European countries.

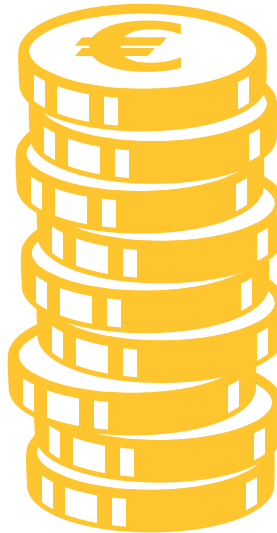
Figure 1: Rates of new strokes and deaths due to stroke per 100,000 inhabitants, adjusted for age and sex, in 1995 and 2015





34%

more strokes



€45 bil.

total cost of stroke

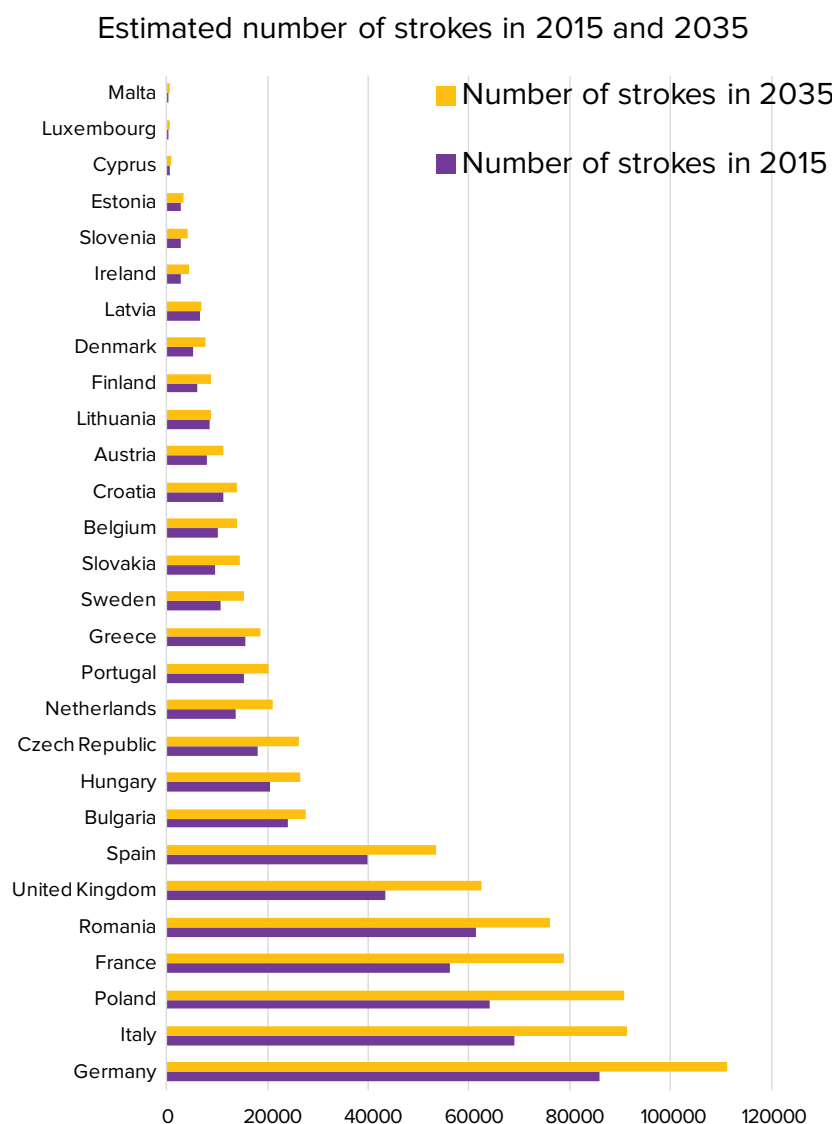


Future projections

The evidence shows that age-adjusted incidence rates for stroke are falling. This trend is welcome, but it is outweighed by our ageing population. Improved survival rates from stroke mean there will be more people living with stroke as a long-term condition. Using GBD 2015 data together with demographic projections for EU member states (Eurostat data) we calculated estimates for the absolute number of stroke events, stroke deaths, and stroke survivors in 2035.

The annual number of stroke events in the EU will increase from 613,148 in 2015 to 819,771 in 2035 an average increase of 34%. Due to different demographic projections, the % change will vary from 2% in Lithuania to 78% in Luxembourg. With the generally improved survival after stroke, this will lead to a significant increase in the number of people living with stroke as a chronic condition from 3,718,785 in 2015 to 4,631,050 in 2035, an increase of almost one million or 25% across the EU.

Figure 2: Estimated number of stroke events in 2015 and 2035 in EU member states



DATA COLLECTION RECOMMENDATION:

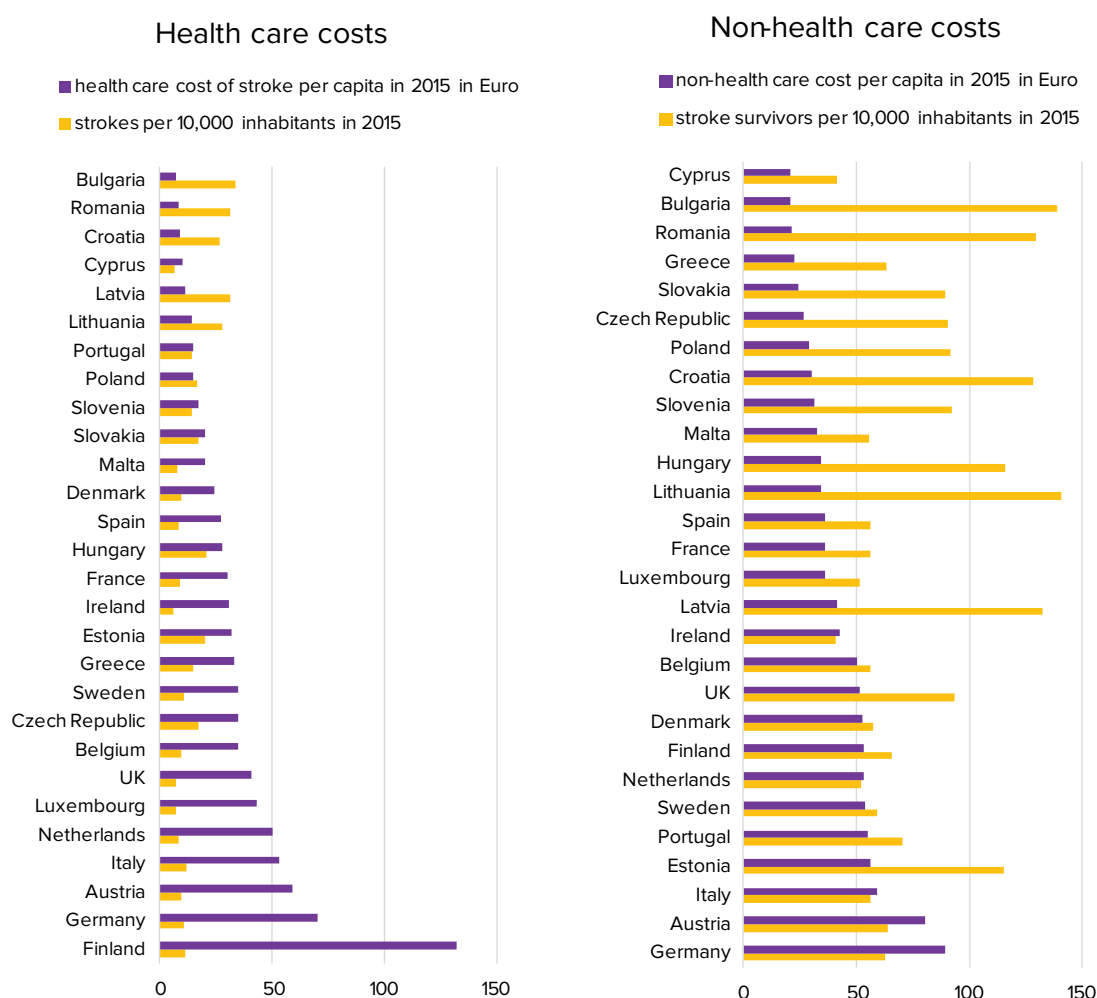
There is a lack of unified data about stroke and stroke outcomes. European-wide comparisons of stroke and stroke care are vital to help each country prevent stroke and provide better care and support for everyone affected by stroke. To make accurate comparisons between different countries, populations and health systems we need agreed and coordinated Europe-wide data collection. Therefore, European policy-makers, in particular the European Commission and the Joint Research Centre, should support and promote the use of a robust Europe-wide stroke register to assess quality of care along the whole stroke pathway.

The economic burden of stroke

In the EU, the direct healthcare cost of stroke was estimated at €20 billion in 2015. Nearly three-quarters of these costs (72%) were in-hospital care. Per capita spending on stroke varied by a factor of 19 between Bulgaria (€7) and Finland (€132), and bears no relation to the number of strokes per inhabitants (Figure 3). The overall health expenditure varies hugely between EU member states but the proportions of overall health expenditure spent on stroke varied less, from 4% in Finland and Hungary to under 1% in Denmark.

However, direct healthcare costs are less than half of the total cost of stroke, which was estimated at €45 billion in 2015. Non-healthcare costs include informal care costs and productivity lost due to death and morbidity. Informal care costs, i.e. the opportunity cost of family members and friends providing care, were estimated at €15.9 billion in the EU in 2015, with productivity losses due to death and morbidity at €9.4 billion. The huge economic burden of stroke is borne by society as a whole via tax payments and insurance contributions, but significantly also by the individual stroke survivors and their families and friends.

Figure 3: Healthcare and non-healthcare costs of stroke per capita in 2015 in Euro and crude incidence and prevalence of stroke per 10,000 inhabitants in 2015 (GBD 2015)



The impact

of having a stroke is much more than economic. Survivors commonly experience long-term disability including problems with mobility, vision, speech, memory, personality changes, fatigue and depression. By their nature, the impacts of these impairments are complex and hard to quantify.

Stroke support organisations often hear of the pressures stroke survivors face including social isolation, family breakdown, financial difficulty and inability to access help.

“The challenges [for stroke survivors and families in Greece] are day to day living.... But also, it is becoming a viable member of society again and I think that’s important worldwide, not only in [my country] Greece. In Greece you do have support, but you do have the immediate consequences of stroke which are quite devastating for everybody.”

(Stroke clinician and stroke support organisation volunteer, Greece)



Healthcare Planning Recommendation

The number of people having a stroke and the number of people living with the long-term effects of stroke will rise in the coming decades. Effective healthcare planning and adequate resource allocation across Europe is needed to deal with this, taking into account that the financial burden of stroke is to a large extent borne by stroke survivors themselves and their families.

European stroke data – registers and audits

Within the EU, there are numerous stroke registers at local, regional, national, and sometimes international levels collecting varied data on stroke epidemiology and/or acute care with different methods. International stroke registries with standardised datasets of acute care quality do exist, e.g. SITS-MOST and RES-Q (see example), but data reporting is voluntary and therefore coverage varies significantly and limits international benchmarking.

There are also some well-established audits of stroke care that gather real-time evidence of what happens to patients and their outcomes. This information can be used as a driver for improvements in the organisation and quality of care.

European Stroke Data Recommendation

The European Commission and the Joint Research Centre should support and promote the use of a robust Europe-wide stroke register including instruments to assess quality of care along the whole stroke pathway.

The Safe Implementation of Thrombolysis in Stroke-Monitoring Study (SITS-MOST) includes over 160,000 stroke patients from over 70 countries, primarily those who received thrombolysis. All European countries are registered, but reporting rates vary hugely between countries, either due to low thrombolysis volumes, or poor interest in reporting data (19,102 cases from Czech Republic (4th largest contributor to SITS and largest by number of inhabitants), compared to 1 from Romania, 2003-2016).

The Registry of Stroke Care Quality (RES-Q) is an important project within the European Stroke Organisation (ESO). It was launched in May 2016 and targeted primarily at Eastern European countries. It is a multi-national study designed to document the quality of stroke care. Standardised measurements have been agreed by an international working group (Norrving 2015) and include the availability of stroke units, brain imaging, vascular imaging, cardiac arrhythmia detection, thrombolytic therapy, and other factors.

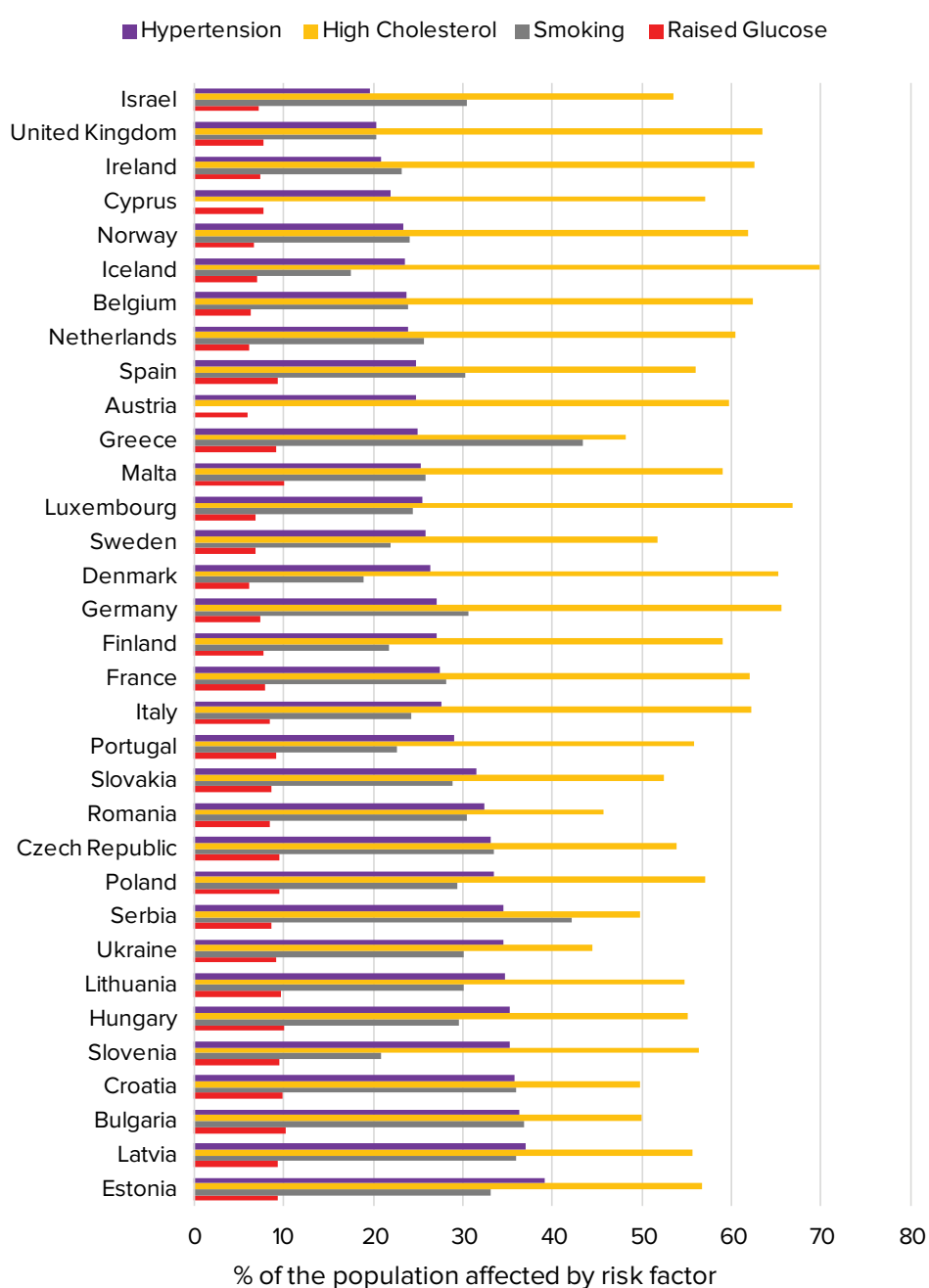
STROKE PREVENTION AND CARE ACROSS EUROPE



Preventing stroke

Stroke is preventable. Ten modifiable risk factors account for around 90% of the risk of stroke. The most important are high blood pressure (hypertension), high cholesterol, smoking, obesity/diet, atrial fibrillation and diabetes. The proportion of people with these risk factors varies greatly between countries (Figure 4).

Figure 4: Proportion of the population affected by some of the major vascular risk factors



"I suffered from stroke at the age of 25 and didn't know anything about the issue. I wish I knew, because knowing the symptoms of stroke would help me recognise the wake-up call - TIA (so-called mini-stroke) and perhaps prevent my stroke."

(Female stroke survivor,
Poland)

"I suffered a cerebral venous thrombosis in 2011 (I was 34 years old)...I was a journalist, editor of a weekly magazine...I did not have the time nor patience to practice sport...In addition to stress and sedentary lifestyle, also the use of oral contraceptives contributed – in the opinion of doctors - to my stroke"

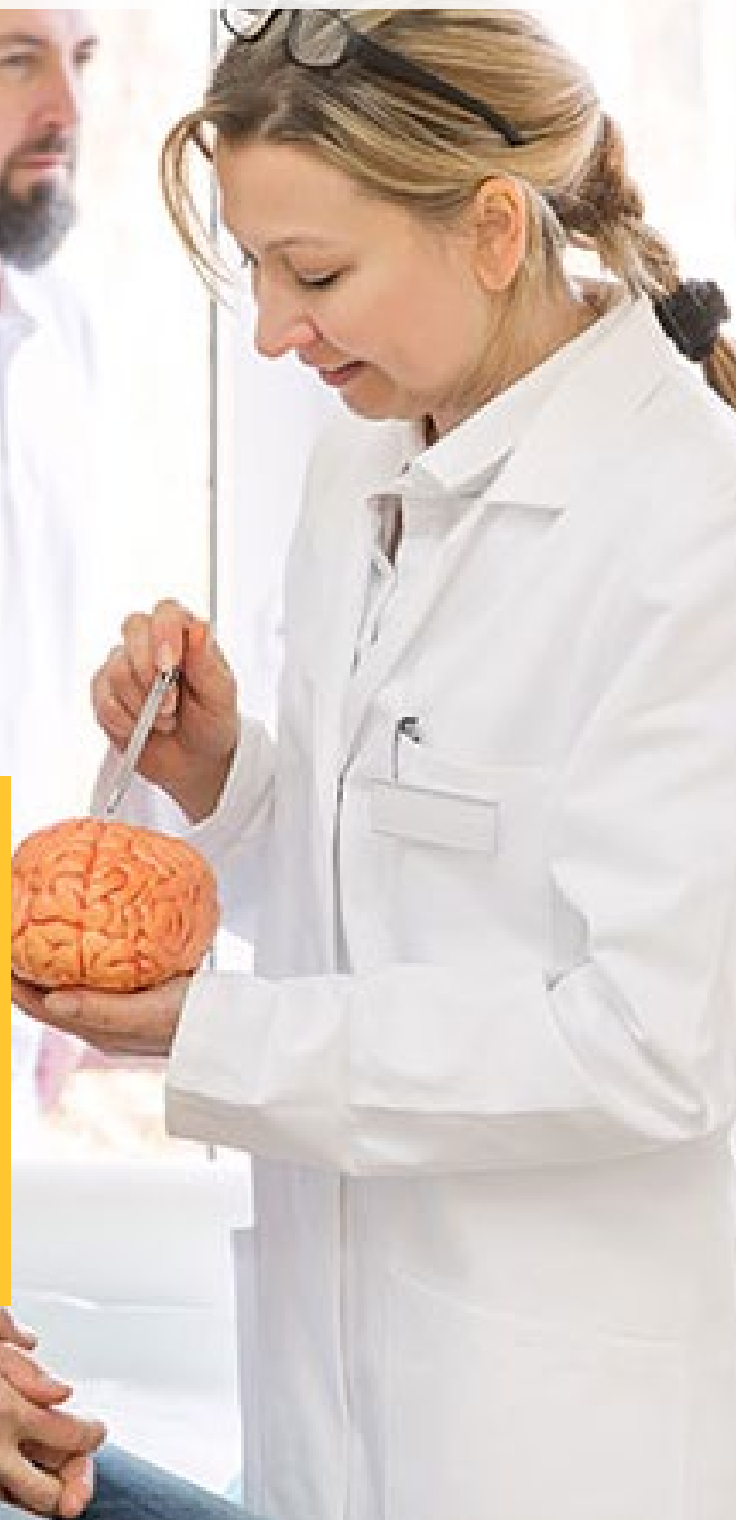
(Female stroke survivor,
Portugal)



Across Europe, the level of public awareness of stroke risk factors and symptoms is poor as shown in numerous Eastern and Western European studies.

Most countries have undertaken educational campaigns that aim to raise awareness of stroke risk factors and encourage people to adopt a healthier lifestyle, yet only some of them have been evaluated systematically. The few that have been assessed showed varied success with regards to risk factor knowledge or, even more importantly, behaviour change.

Example from Finland: The Finnish Brain Association national blood pressure campaign was awarded a World Stroke Organisation prize in 2016. The campaign used radio, social media, a website and digi-screens in trams and metros. The radio campaign reached 2.85 million Finns. 121 pop-up measurement points were set up and 6,002 people's blood pressure was measured.



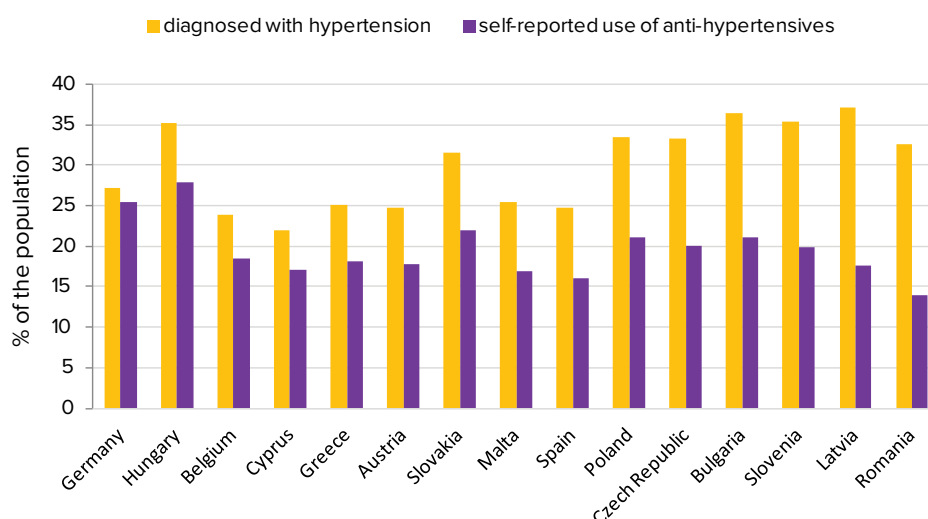
Hypertension

Hypertension, the most important risk factor for stroke, is estimated to affect 20% of the general population in the UK, compared to 39% in Estonia (2014 data). Eastern European countries are generally estimated to have higher rates of hypertension than Western European countries.

The vast majority of European countries have developed national evidence-based guidelines for the management of hypertension.

However, the data show significant under-treatment (Figure 5). Well below half of all patients on medication actually have their blood pressure controlled. Similarly, studies of stroke populations have shown that, in those with known high blood pressure, less than 40% achieved adequate control (includes data from Croatia, Czech Republic, Germany, Ireland, Poland).

Figure 5: Population affected by hypertension and self-reported use of antihypertensives (Eurostat 2008 data, ranked by the relative gap between hypertension and use of antihypertensives)



Atrial fibrillation

Atrial fibrillation (AF or A-fib) is an abnormal heart rhythm. It is estimated to increase the risk of stroke 3 to 5-fold and to be linked to around a quarter of all ischaemic strokes. Due to Europe's ageing population and AF's association with age, the number of patients with AF in Europe is expected to rise from 8.8 million in 2010 to 17.9 million in 2060. However, screening is not yet routinely done and European screening studies have found significant under-diagnosis. Most European countries have national guidelines for AF management.

Anticoagulation rates reported from large surveys recruiting patients from specialist cardiology set-ups are encouraging with reported rates of 70% or higher. But studies using primary care or stroke register data show much lower anticoagulation rates of between 20 and 40% of AF patients. There is evidence that older people and those at high risk of having a stroke are even less likely to be treated. The guidelines are, too often, not being implemented.

Stroke Prevention Recommendations:

Across the EU we need rapid and concerted action to prevent stroke and, especially, improvement in the detection and treatment of hypertension (high blood pressure) and atrial fibrillation (an abnormal heart rhythm with rapid and irregular beating).

A more systematic, evidence-based approach to public education across the EU is required to improve knowledge of the modifiable risk factors for stroke, i.e. an awareness that these factors significantly increase a person's risk of stroke, but can be treated in most cases. Joining forces with public education efforts in relation to other cardiovascular diseases, such as diabetes, could create a more powerful message and greater impact.

Emergency response to stroke

The quicker someone is seen and treated by specialist stroke teams, the better their recovery - in stroke care 'time is brain'. Clot-busting treatment (thrombolysis) is time dependent and must be administered within 4.5 hours. Practically it means that:

The person having a stroke or bystanders need to recognise symptoms and contact emergency services.

Emergency services need to be trained to screen for stroke, and pre-notify and transfer patients to the appropriate medical facility

Hospitals need to develop and adhere to specific stroke care protocols.

Avoidable delays have been identified at all of these stages across many European countries, including those with highly organised stroke services. These delays are an important reason for thrombolysis (clot-busting treatment) and thrombectomy (mechanical clot removal) still being under-performed within most of Europe, including the West.

Public awareness of stroke as a medical emergency is poor across Europe, and this is an important reason for pre-hospital delay. In a large study of public knowledge in Austria, France, Germany, Italy, the Netherlands, Poland, Russia, Spain and the UK, 19% could not identify any stroke symptoms and only 51% would call an ambulance if they suspected someone was having a stroke.

Educational programmes to increase awareness of stroke at the population level are recommended in the European Stroke Organisation (ESO) guidelines and many have been undertaken. However, as with education around stroke risk factors, systematic evaluation of public awareness programmes is poor and there is a need to evaluate the impact of countries' efforts as a first step in improving their effectiveness. It is clear that raising public awareness of stroke needs to be a continuous, sustained effort.

"I never had before thought about that disease; I had no way of [knowing], nobody in the family had ever had a stroke. I thought everything was fine, and I was relatively young. I was 47."

(Female stroke survivor,
Austria)



Example from the Czech Republic: The Hobit Programme (acronym for HOdina Biologie pro živoT) was initiated to increase the response by school children to stroke and heart attack symptoms. HOBIT 1 ran from 2009 to July 2015, and confirmed excellent feasibility and sufficient efficacy of the innovative web-based multimedia education program for children.

There is some evidence from most European countries that professionals (paramedics, emergency or other physicians) have undergone education about stroke as a medical emergency but the extent and intensity of the training is largely unclear. There are varied results in the very few studies into the impact of training programmes.

Stroke specific training for medical staff is often part of a wider effort of implementing more efficient emergency care pathways on a national or regional level. A system of ambulance stroke screening and pre-notification of the assigned hospital is a central part of most pathways introduced over the last decade in Europe and has shown generally good results.

"Both my stroke and my heart attack were only diagnosed two days later. I did not receive the right treatment in two different hospitals, in two different countries [Luxembourg and the Netherlands]"

(Female stroke survivor,
when aged 37)



Example from Finland: The “Helsinki Model” involved several system improvements rolled out at Helsinki University Central Hospital in Finland between 1998 and 2011, including ambulance pre-notification, direct triage to CT scanner, and administration of thrombolysis directly in the CT suite. In-hospital delays as analysed with annual median door-to-needle time were reduced from 105 minutes in 1998 to 20 minutes in 2011. Those system changes were successfully replicated at The Royal Melbourne Hospital in Australia bringing door-to-needle time down to 25 minutes.

A key measure to assess delays in hospital and the efficiency of emergency care pathways is how long it takes for someone to get treatment after arriving – the door-to-needle time (DNT). DNTs are generally shorter in centres with higher volumes of stroke patients. Large inequalities in DNTs were found between countries, but particularly also between different centres within the same country. There is an opportunity to further improve emergency pathways in some centres and learn from centres with efficient services and good outcomes.



"I needed almost three days (without being able to speak) to explain to staff that something was wrong with my brain and that they should apply a CT [scan]. The next day (the day my discharge was originally planned) I was informed that I had a left-hemisphere stroke and I had to stay in the hospital. I objected, shaking my head... Unfortunately, despite the great efforts of some institutions and organisations, low knowledge about stroke is still prevalent in the population."

(Male stroke survivor, 50+, Germany - date of stroke December 1997)



Emergency Response To Stroke Recommendations:

We need to reduce delays in people getting emergency stroke care by carrying out continuous education of the public and health professionals to recognise stroke and always treat it as an emergency; and by improving emergency care pathways. There should be enough trained stroke specialists available and acute and emergency stroke services should be organised to maximise patient access to emergency care.

Stroke Unit care

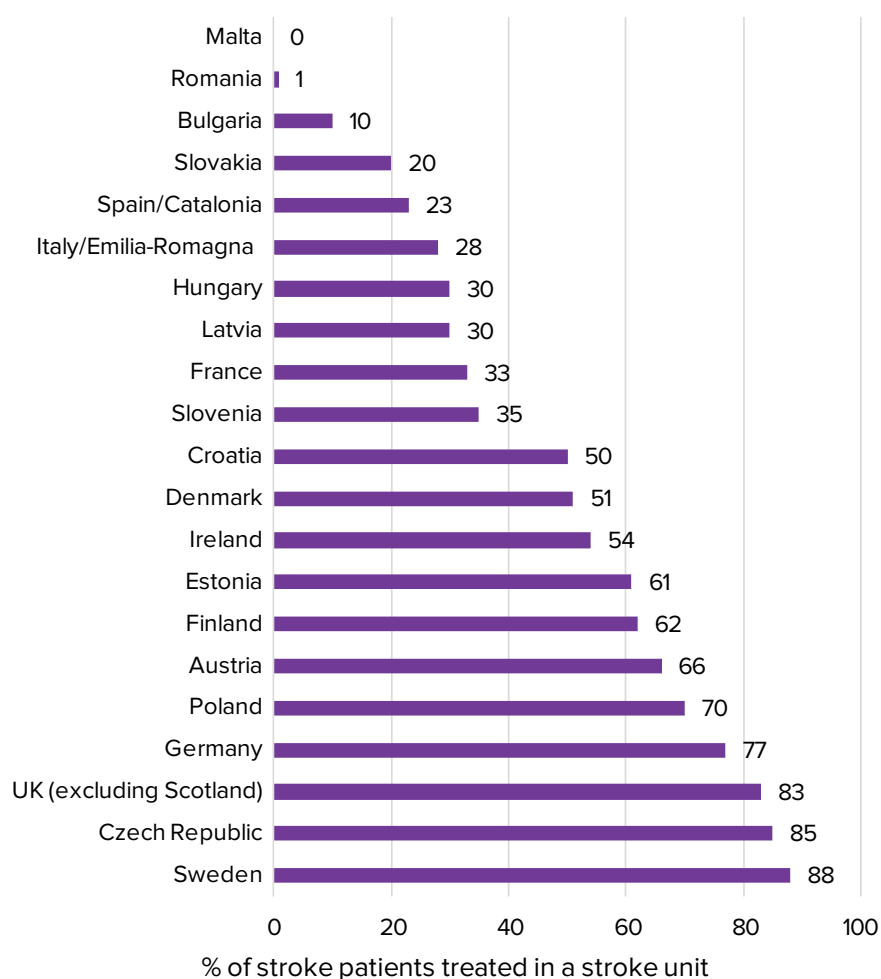
"Stroke patients who receive organised inpatient care in a stroke unit are more likely to be alive, independent, and living at home one year after the stroke" (Cochrane Review 2013). The 2nd Helsingborg Declaration stated "all patients in Europe with stroke will have access to...stroke units in the acute phase...by 2015".

Stroke units save lives and improve outcomes. But despite over thirty years of evidence showing the difference stroke units make and despite their inclusion in European and national guidelines, it is estimated that only about 30% of stroke patients receive stroke unit care across Europe.

Comparing stroke unit provision between countries has caveats, as some data is missing or of poor quality and, although internationally agreed standards have been defined, e.g. ESO Stroke Unit Guidelines, stroke units are not systematically assessed against these standards across all of Europe. Despite these uncertainties, significant inequalities are clear.

We found large differences within Europe in the proportion of stroke patients treated in stroke units, ranging from <10% in Romania and Bulgaria to >85% in Sweden (Figure 6). Lower rates were generally observed in Eastern European countries, but variations within Eastern Europe are significant as well.

Figure 6: Percentage of stroke patients receiving stroke unit care

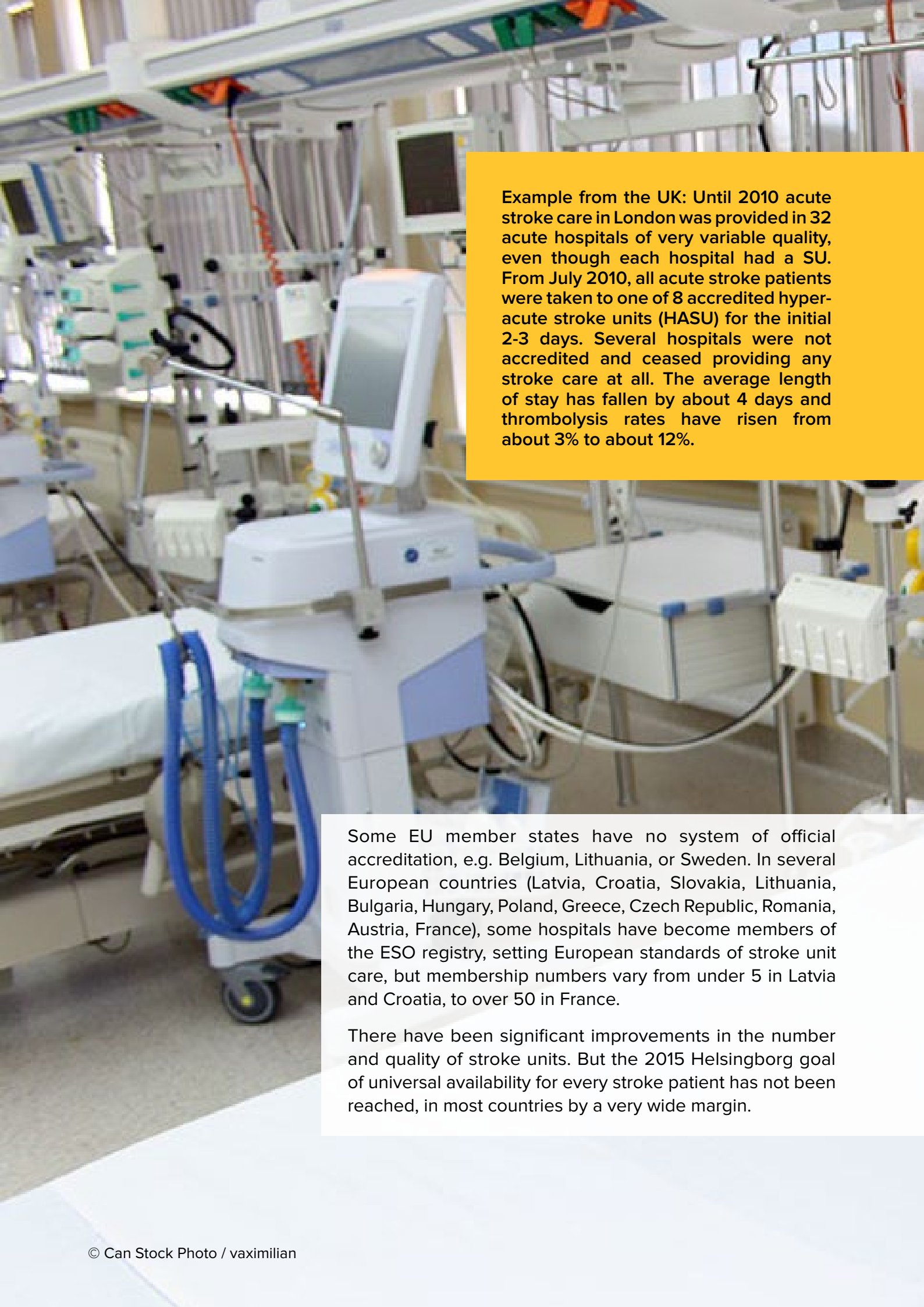


There are also strong inequalities within many countries, often between major cities and rural areas. Variations within countries might be as large as or even larger than variations between country averages.

Stroke units should provide coordinated, multidisciplinary care by specialised personnel. Several initiatives to improve the quality of stroke unit care have been launched. The Stroke Unit Trialists' Organisation and some national stroke organisations (e.g. Belgian Stroke Council, German Stroke Society, Spanish Neurological Society) have issued guidelines for the creation of stroke units using standards based on evidence or expert consensus. A system of official

accreditation has been introduced at a European level (e.g. ESO Stroke Unit and Stroke Centre Certification Platform) and at several national levels, and hospitals are encouraged to apply.

Certification is now mandatory in some EU member states, e.g. France, and financed and organised by governmental agencies, but voluntary in others, e.g. Germany, where it is organised by the German Stroke Society, the German Stroke Foundation and an accredited certification institution and paid for by the hospital.



Example from the UK: Until 2010 acute stroke care in London was provided in 32 acute hospitals of very variable quality, even though each hospital had a SU. From July 2010, all acute stroke patients were taken to one of 8 accredited hyper-acute stroke units (HASU) for the initial 2-3 days. Several hospitals were not accredited and ceased providing any stroke care at all. The average length of stay has fallen by about 4 days and thrombolysis rates have risen from about 3% to about 12%.

Some EU member states have no system of official accreditation, e.g. Belgium, Lithuania, or Sweden. In several European countries (Latvia, Croatia, Slovakia, Lithuania, Bulgaria, Hungary, Poland, Greece, Czech Republic, Romania, Austria, France), some hospitals have become members of the ESO registry, setting European standards of stroke unit care, but membership numbers vary from under 5 in Latvia and Croatia, to over 50 in France.

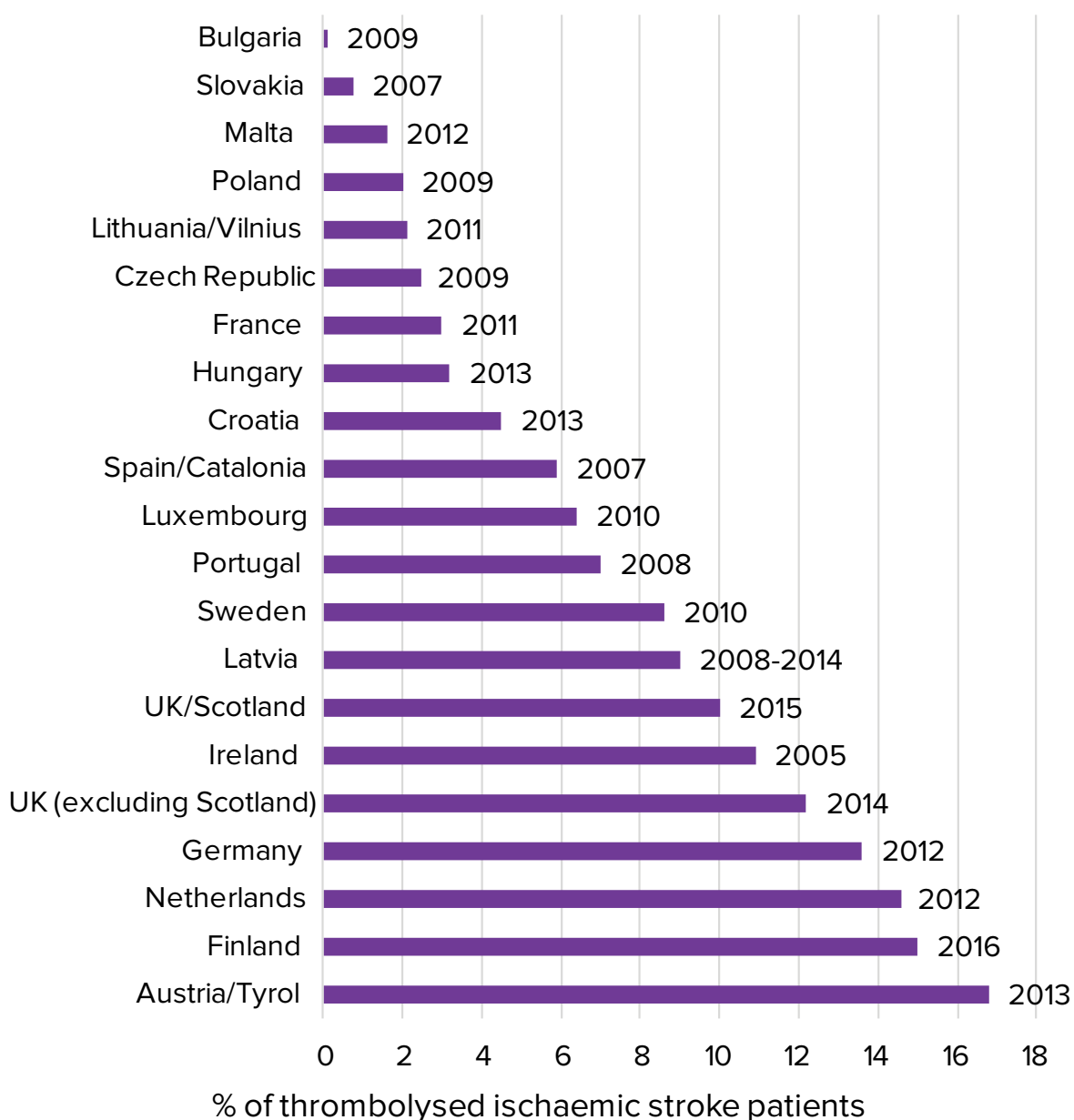
There have been significant improvements in the number and quality of stroke units. But the 2015 Helsingborg goal of universal availability for every stroke patient has not been reached, in most countries by a very wide margin.

Thrombolysis

The benefit of thrombolysis for acute ischaemic stroke is well established. All EU member states have introduced national guidelines for thrombolysis. Large differences in the methodologies and representativeness (on a national level) of studies of thrombolysis rates in countries across Europe limit comparisons, but rough trends can be observed.

Thrombolysis rates have increased in most European countries, but rates are generally lower in Eastern Europe (Figure 7). As with stroke unit care, European countries reported significant variations in thrombolysis rates between regions, with rates being generally much higher in urban areas) and particularly between individual stroke centres.

Figure 7: Thrombolysis rates in national/large regional audits or national estimates in the year indicated



Increased rates of thrombolysis have followed the development and implementation of local and national strategies in many countries leading to structural changes of stroke care: the implementation of stroke unit care; the centralisation of stroke services; and hospital pre-notification systems, for example. Funding systems for thrombolysis were improved in some countries, e.g. Poland, and the treatment window for thrombolysis was extended from 3 to 4.5h in European and national guidelines. Telemedicine networks have been developed in several European countries, whereby smaller hospitals are linked to large centres to support acute stroke treatment outside large urban centres.

Despite improvements, thrombolysis rates are still significantly below expectations across Europe. Barriers to the delivery of thrombolysis are numerous and complex. The most significant barriers are pre- and in-hospital delays (see Emergency response to stroke). But lack of specialised units or staff, lack of diagnostic equipment, insufficient funding (e.g. 35% of Croatian centres were found to be restricted due to

"I was lucky enough to be in a Clinic which is across the street from the Emergency Centre. The full diagnostic was done within the first hour of the onset of symptoms. I received thrombolytic therapy and recovered completely, as if I never had a stroke".

(Male stroke survivor, Serbia)



financial limitations) and decentralised systems of stroke care have all been linked to lower thrombolysis rates.

Thrombectomy (mechanically removing blood clots) is currently being introduced in many European countries, as there is good evidence to support its use (where clinically appropriate). In most countries it is not available 24/7 or in all regions while in some countries it is not yet available at all.

Acute Care Recommendation:

Stroke units save lives and improve outcomes so improving stroke unit provision is a priority. Currently only 30% of people who have stroke get treated in a stroke unit. SAFE believes everyone who has a stroke should be treated in a specialised stroke unit that meets Europe wide agreed organisational and quality standards. Efforts are required to further increase stroke unit care and specialised personnel in many Eastern European countries, but also Western European regions with low availability.

Thrombolysis is still under-performed across all of Europe. Structural changes to acute stroke care within the respective national and local context could help to improve thrombolysis rates and patient outcomes.

Medical and technological advances leading to new treatment options, e.g. thrombectomy, must be made available to all patients across Europe, for example by creating a network of collaborating hospitals.

Rehabilitation in hospital and in the community

Stroke survivors across the EU are waiting too long to have their immediate rehabilitation needs assessed and therapies started. Once they get rehabilitation it is often not intense enough, is for too short a time, and fails to address ongoing issues, such as mental health issues including depression. Very few people get follow-up reviews. In the long term, support is too often non-existent.

Rehabilitation is a process involving physical and psychological therapies that enables people to regain abilities to complete everyday activities. Stroke survivors should be assessed for their rehabilitation potential and should begin therapies as soon as it is medically safe. Rehabilitation should continue for as long as survivors are making progress, which may be for several months after the stroke. But in some countries, specialised neurology or stroke inpatient rehabilitation centres have very limited capacity or are non-existent. Psychological therapy and occupational therapy are two relatively poorly developed or resourced specialisms for stroke survivors in several European countries.

"I think that receiving psychological support, not only for myself but also for my family, since the beginning of the 'illness' would have been very positive...It was very difficult to be away from my children (while in rehabilitation centre) ... the fear of dying or being stuck in a wheelchair forever ..."

(Female stroke survivor,
Portugal)



The provision of rehabilitation across the EU is not widely monitored or benchmarked, especially in terms of therapies that patients may receive after discharge from hospital. A minority of EU countries, such as Sweden and the UK, have well-established audit programmes that include recording compliance with early assessment, mobilisation and rehabilitation guidelines. These suggest that patients receive therapies during only brief periods of each day in hospital, due to time pressures and staff availability. In several countries, there is very limited access to therapies for patients once they are at home, and inequality of access to services between different regions of the country, as well as a lack of coordination between acute, inpatient and community care.

"I got the privileged service from the insurance; they wanted me to come back to work, so they invested in me. And this is today's problem; they don't do it any longer [i.e. invest in rehabilitation], and that is why I am fighting for the patients, because I received such good help and I am now really in a good shape."

(Female stroke survivor,
Austria)



Early supported discharge schemes are where stroke survivors' rehabilitation continues in their own home at the same intensity as in hospital. People can return home earlier where they are more likely to regain independence in daily activities. Stroke unit care with early supported discharge is cost-effective compared with care on the general medical ward or on a stroke unit. Despite these advantages, with

a few exceptions, such services have been slow to develop in Europe. Lack of capacity in community provision means stroke survivors can experience unnecessarily prolonged stays in hospital or rehabilitation centres.

There are no formal arrangements in over a third of EU member states to provide follow up reviews. Outpatient-based rehabilitation is unavailable in two in five EU member states.

Rehabilitation Recommendation:

We need a step change in the provision of rehabilitation and long-term support for stroke survivors and their families. All stroke survivors should get an early assessment for rehabilitation in hospital, and receive therapy at an appropriate level both in hospital and following discharge. Post-hospital reviews should be available to all stroke survivors, wherever they live in Europe, and they should be able to get therapy (including for their psychological and non-physical needs) for as long as they need it.



Long term support for stroke survivors and families

As well as medical and physical therapy needs, stroke survivors and their families may face a number of difficulties adjusting to life after stroke, including emotional or psychological problems, extra costs of living (e.g. transport, rehabilitation, medications), and difficulties with finding suitable work or returning to work and therefore loss of earnings.

Although stroke is recognised as a long-term condition, the practice of reviewing survivors' rehabilitation and social support needs following discharge from medical care is not widely implemented across Europe. The organisation and delivery of longer term care is lagging behind the advances in knowledge and treatment that stroke survivors generally can expect to benefit from at the acute stage.

"My GP was the best, she was fantastic. [But] when it came to the real crunch of it, that big part down the line, I spoke to her and she hadn't got a clue[about longer term support]. It's like thinking, how do you educate the medical profession to better understand about the whole person's needs? Because it all focuses around 'treat them in the hospital, rehabilitation, get them out into the community, six weeks' support ... and then you're on your own.' "

(Male stroke survivor,
UK)



Example from East Saxony, Germany: Post-acute case management. This trial (pilot phase) placed patients on a standardised post-stroke pathway with a certified case manager. The pathway comprised patient education, quarterly check-ups for vascular risk factors and adherence to antithrombotic/anticoagulant medication in addition to usual care. Compared with usual care alone, the intervention was more successful in modifying two important stroke risk factors; intervention patients also reported higher satisfaction with their healthcare and quality of life after 12 months.

"It was very hard when they told me I couldn't go back to work and, during the rehabilitation period, I got very depressed. My therapists saw that one day I was making progress and the next day I wasn't. It was more difficult when I got back to Norway, having been an active person, taking initiatives and now I was just sitting there. That is a tremendous challenge because it is a completely new life that you move into."

(Male stroke survivor,
50+, Norway)



Stroke survivors and their families in different countries receive varying amounts of financial and practical support with managing life after stroke. For example, formal care services are funded less, with relatively more care provided by patients' families, in central Europe (Austria, Germany, Netherlands, France, Belgium, Czech Republic, Poland) and southern Europe (Spain, Italy, Greece) compared with northern Europe (Denmark, Ireland, Sweden).

Many countries' health and social care policies aim to support people living with disabilities in the community although such strategies and programmes have commonly been hit by austerity measures. In some of the newer EU countries there is a persistent focus on institutional care. In many countries general practitioners (GPs) are seen as the gatekeepers for all aspects of treatment, services, secondary prevention and emotional support.

However, GPs generally see too few stroke survivors and have too little time with patients to be able to understand and meet their often complex needs. SAFE believes that stroke training and reimbursement frameworks for GPs need improvement.

It is clear that long-term support for stroke survivors and their families is falling far short of their needs. Too few stroke survivors get an early assessment for rehabilitation and reintegration into society while in hospital, and the therapy they get there is often limited. Getting a post-hospital review and accessing therapy after leaving hospital are rare in many countries and regions in Europe. The psychological and emotional impacts of stroke are very often ignored.

"You don't want life to change, it's too hard... we could not talk about it and each of us kept our painful feelings inside. My sister was afraid of him when he looked at her... but she was only 4 and couldn't understand "why us". My father stayed a long time in a training centre and after 6 months came home for good. It was very difficult, we had to rearrange the house, but worse, I did not want my friends to come to our house any more just because I was ashamed of him."

(The daughter of a male stroke survivor, France)



"Despite being in a quite unusual situation among my friends, I haven't lost hope. Life after stroke is different, but doesn't have to be necessarily worse."

(Female stroke survivor, Poland)



Life After Stroke Recommendations:

Across Europe there is very little provision for the long term needs of stroke survivors. SAFE calls on all European countries to consider implementing frameworks for support after stroke, ensuring a holistic approach to tackling “life after stroke” issues and recognising the roles of carers and families.

Recognising the value of provision of emotional, practical and financial support for stroke survivors and their families, SAFE believes that stroke support organisations can play an important role in the overall stroke pathway. Health authorities and Governments should provide funding to help build their capacity.

